#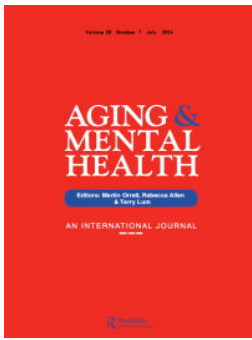 Strategic and operational issues in sustaining community-based dementia support groups: The Get Real with Meeting Centres realist evaluation part 2

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Strategic and operational issues in sustaining community-based dementia support groups: the Get Real with Meeting Centres realist evaluation part 2

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ABSTRACT

Objectives: Support for people with dementia in their communities is neither robust nor consistent in the UK, often bolstered by third sector/grass-roots initiatives facing formidable challenges in sustaining long-term. The Get Real with Meeting Centres project explored factors involved in sustaining one such form of community-based support. This is the second of two linked articles outlining learning from this realist evaluation of Meeting Centres (MCs) for people with dementia and carers, which focusses on findings regarding their operational and strategic running.

Method: Semi-structured interviews and focus group discussions were conducted with 77 participants across three MC sites in England and Wales, including people living with dementia, informal carers, staff, volunteers, trustees, and supporting professionals/practitioners. Data were themed, then analysed using soft systems methodology and realist logic of analysis.

Results: Forty-two 'context-mechanism-outcome' statements were generated, explaining how background circumstances might trigger responses/processes to produce wanted or unwanted outcomes regarding three key areas for MC sustainability: *External relationships and collaboration; Internal relationships and practices;* and *Finances and funding.*

Conclusion: Collaboration is essential to sustaining community-based initiatives such as MCs, particularly between local community and regional level. MCs need to be vigilant in mitigating pressures that create 'mission drift', as targeting a gap in the care pathway and maintaining a person-centred ethos are central to MCs' appeal. Stable, ongoing funding is needed for stable, ongoing community dementia support. More formal recognition of the value of social model community-based initiatives, helped by improved data collection, would encourage more robust and consistent community dementia support.

Introduction

As in many nations, support for people living with dementia in their communities is neither robust nor consistent across the UK population. Before the COVID-19 pandemic, social care provision was described as 'precarious and dysfunctional' (CQC, 2019) or 'broken down' (Incisive Health, 2019) in some parts of the country. Since the pandemic, services have struggled to recover, with support often difficult to access or delayed for many due to service capacity issues (CQC, 2023). With an aging population (ONS, 2019), and the numbers of people living with dementia predicted to grow significantly between now and 2050 (Luengo-Fernandez & Landeiro, 2023), policy has for some time pointed to the need to move towards a model of social care where more people are cared for and supported at home, in the community (DHSC, 2015, 2022). With similar situations across various nations, improving the provision of community services for people affected by dementia, and developing dementia-friendly communities (DFCs), remains a global health goal (ADI, 2022; WHO, 2017).

Third sector and grass-roots community dementia support

It is in this climate that many third sector and grass-roots initiatives offering support in the community for people affected by

dementia attempt to operate. These community-based dementia-friendly initiatives (DFIs) are often in the form of groups and activities for people with dementia and family/informal carers, and aim to fill the widespread gaps in more formal support. However, such initiatives face a formidable challenge in sustaining long-term. The SCI-Dem review (Morton et al., 2021) found that, while much talked about in practice and policy, the challenges of sustaining such community support had received very little research attention. However, staffing issues, the support of other services and organisations, and funding/income were key factors. In particular, proactive measures to raise awareness and involve other organisations, avoiding conflict and sharing knowledge and resources, were found to help in securing essential support, but required significant maintenance through skilled communication, planning and working practices. Skilled financial planning and management was needed but the often short-term nature of funding was a significant barrier to maintaining provision and retaining deep learning and experience. Challenges in meeting funders' requirements and overcoming logistical barriers were especially acute for small-scale and rural groups.

The Get Real with Meeting Centres project

The Get Real project aimed to test (confirm, refute or refine) the conclusions of the SCI-Dem review with primary research, by evaluating

a specific type of intervention, Meeting Centres (MCs), in a 'real world' setting. Based on a successful Dutch model, MCs are a form of community-based, community-led DFI currently proliferating worldwide, and present in the UK since 2015 (Brooker et al., 2018; Dröes et al., 2004; Mangiaracina et al., 2017). Usually run by different third-sector/community organisations in different areas, MCs have grown from 13 in the UK prior to the pandemic to about 70 in 2024. MCs are distinct from day care, supporting people with dementia and those who support them (e.g. children, partners, and friends) together, and connecting people to each other and their community. They comprise a small social club based in a community building, operating up to three times a week. The features of MCs (Brooker, 2020; Evans et al., 2023) are designed to help people make emotional, social and practical adjustments to living with dementia, with a small team of staff and volunteers trained in person-centred care and the underpinning 'adjusting to change' model (Brooker et al., 2017). MCs usually provide a programme of activities based on the wishes of people who attend, including movement and co-ordination (e.g. seated exercise, tea dances, gardening, and walks), talks, quizzes, discussions, visits to local attractions, arts and crafts.

Running from January 2021 to March 2023, the Get Real project was funded by the National Institute for Health and Care Research's (NIHR) Research for Social Care (RfSC) programme. It aimed to investigate the factors affecting the sustainability of MCs, to learn lessons for current and emerging MCs, and similar DFIs. If such initiatives cannot survive long term, the gaps in provision they seek to fill will remain. Research into adaptively implementing MCs in Italy, Poland and the UK has been carried out, regarding how those MCs fit into their local dementia care pathways (Szcześniak et al., 2018) and identifying barriers and facilitators to implementation at three levels: micro (user/primary processes), meso (inter-organizational/social context), and macro (healthcare system, legislation, and policy) (Meiland et al., 2005; Van Mierlo et al., 2018). However, the Get Real project is the first research to focus specifically on MC sustainability in the UK context, with MCs that have sustained for a number of years.

This is the second of two linked articles outlining results from a realist evaluation conducted at case study MCs sites in England and Wales. This study has been exploratory and wide ranging in the variety of issues identified and investigated. To allow for a thorough and nuanced account of the learning from this study, the findings have been split into two articles, each with a different focus. Part 1 (Morton et al., 2024) focused upon the membership of MCs, including referrals and reach. This second article investigates how decisions and activities regarding the operational and strategic running of MCs impact upon their sustainability, including the role of collaboration between organisations and how finances are managed.

Methods

This study is registered with ISRCTN, ref: 39861, and a full protocol for the project has been published (Morton et al., 2022). The core work package of the Get Real study comprised a realist evaluation (Pawson & Tilley, 1997) that incorporated mixed methods of data collection and analysis. Qualitative data was collected *via* semi-structured interviews and focus group discussions with participants in a range of roles at each of the case study sites.

Meeting centre case study sites

Three case study research sites were included in the study. These were MCs that have sustained for more than three years in England and Wales, while taking contrasting approaches to implementing and running an MC. They comprised: An MC in a small market town in Herefordshire, England; An MC in a larger market town in Worcestershire, England; A cluster of four federated small town MCs run by a single organisation within the rural county of Powys, Wales.

Participants

To ensure that the interviews and focus groups captured a range of perspectives and experiences of MCs, participants were purposefully selected. They included attendees living with dementia; attendees supporting someone with dementia; staff and volunteers; trustees; and external health/social care professionals and other stakeholders. MC leads and staff helped to identify and approach MC attendees, and worked with the research team to invite them to participate in the study and make an informed decision on taking part (Morton et al., 2022). They also helped identify external collaborators to contact as potential interviewees. All participants were required to provide informed consent and sign a consent form before taking part in any interviews or focus groups. Favourable ethical opinion was granted by Health Research Authority research ethics committee Wales REC4 (ref: 21/WA/0185).

The interviews and focus groups were conducted between July 2021 and July 2022, taking place either on-site at an MC or online/by telephone depending on then-current pandemic restrictions and participant preferences. Additional 'update' interviews with MC leads (managers or trustees) from each case study MC took place in September and October 2022.

Interview schedules and focus group topics

Topic schedules for both semi-structured interviews and focus group discussions (Morton et al., 2022) were developed with public stakeholder involvement. Areas for investigation were guided by findings from the SCI-Dem review (Morton et al., 2021), using the elements of a soft systems methodology 'BATWOE' structure (Checkland, 1999; Dalkin et al., 2018): Beneficiaries (who the system aims to help); Actors (people's roles and functions in the system); Transformations (how an MC went from start-up to established and thriving); Worldview (opinions on how well things work or should work); Ownerships (who or what can influence or thwart success of an MC); and Environment (contextual factors that could boost or constrain success).

Analysis

Transcripts from the interviews and focus groups were initially coded by theme using NVivo qualitative data analysis software, with both deduction and induction being used to generate the themes, in line with a reflexive thematic analysis approach (Braun & Clarke, 2013). One researcher led on the coding, with a second researcher independently coding 10% of the data. Any discrepancies between coding were resolved through discussion.

Using soft systems methodology (Checkland, 1999), the project team analysed the coded data to develop 'rich picture' diagrams for each case study site (see supplementary file 1) which identified systems of activity pertaining to the sustainability of the MC. By creating and refining root definitions of these systems, a single 'conceptual model' of each identified system was developed, covering all three case study MCs.

The coded data were also analysed using realist logic (Pawson & Tilley, 1997) to develop a series of context-mechanism-outcome configurations (CMOCs) that help to understand how differing contexts might trigger hidden processes (or 'mechanisms') within people and organisations that cause wanted or unwanted outcomes affecting an MC's long-term sustainability. These dual analyses were conducted in tandem and informed each other.

Public stakeholders were consulted for ongoing feedback and advice on all aspects of the project and helped to refine the findings.

Results

As shown in Table 1, a total of 77 people participated in the interviews and focus groups. These comprised 27 participants at the Herefordshire site, 21 at the Worcestershire site and 29 at the Powys MCs. During the data collection period very few carers attended at the Worcestershire MC beyond dropping off and picking up, and no carers at this site agreed to take part in the research. This general lack of engagement from carers at this site was a finding in itself, linked to mission drift (see *Internal relationships and practices* below) and also explored in the previous part 1 article (Morton et al., 2024). It was also likely a result of extra pressures and restrictions facing carers during the COVID-19 pandemic, still ongoing at time of data collection (Morton et al., 2023). Aside from this, overall the range of interviewees was as planned. Attendees living with dementia ranged between 61 and 96 years old, and supporting health and care professionals interviewed included Dementia Advisors, Clinical Commissioning Group leads, third-sector Community Connectors, a local authority adult social care lead, a formal carer, a third-sector personal dementia support worker, and an Ambulance Service representative; other external partners interviewed included dance practitioners, a music practitioner, a walking and heritage practitioner, a GP patient's group and local Rotary Club member, and one researcher (not involved with this study or the project team).

While the interviews and focus groups lasted approximately 10–75 min, the majority took between 30 min and an hour. Of the interviews, 30 were conducted in person, 26 online and seven by telephone, with most in-person interviews being with attendees, carers, staff and volunteers, while online and telephone interviews were predominantly with trustees and external professionals and stakeholders. Only three focus group

discussions were conducted, two online with mainly family carers, one in person with mainly attendees. These were all at Powys MCs, mainly due to restricted access to the physical MCs during pandemic restrictions (Morton et al., 2023).

The content of the transcripts of these was organised under 20 identified themes (see supplementary file 2), which informed a soft systems methodology analysis (Checkland, 1999), where systems activity relevant to the sustainability of MCs were identified, along with their component activities.

Figures 1–3 show the systems of activity regarding external relationships, internal relationships, and finance. These in turn further informed the development of the CMOCs outlined below.

Realist analysis

A total of 94 CMOCs were developed, grouped under 7 broad, overlapping themes: *1. Referrals and the dementia care pathway; 2. Reaching people and membership; 3. Carer engagement and benefit; 4. Venue and location; 5. External relationships and collaboration; 6. Internal relationships and practices; 7. Finances and funding.*

Themes five to seven (CMOCs 53-94), which pertain to the strategic and operational running of MCs, are dealt with in this paper (part 2). A previous paper (part 1, Morton et al., 2024) covers themes one to four (CMOCs 1-52), which pertain to MC membership (reaching people, engagement, access and retention).

External relationships and collaboration

The CMOCs in Table 2 relate to relationships between the MC and organisations operating in the locality around it. As such these CMOCs, along with the conceptual model in Figure 1, relate to the inter-organisational or social context (meso level) of implementing/sustaining an MC. All MCs in this study sustained in part due to collaboration between multiple groups and organisations, whether working together to directly run MCs or in partnerships supporting MCs in some capacity. CMOCs 53-58, regarding community building, partnership and networking, reveal that MCs are more likely to thrive if they can establish a place in their community and build significant support through communicating and forging links with local agencies and organisations. MCs can also act as both a hub and a catalyst to build a dementia-supportive community around. CMOC 59 suggests links between local groups and organisations with a wider remit (regional or national) can bring different strengths and resources together to maximise the chances of an MC's success. However, CMOCs 61-63 show that there are both benefits and risks to sustainability if a larger charity or authority takes over the running of an MC. A key finding is that collaboration clearly aids sustainability, while competition clearly does not (CMOC 60). Collecting and sharing evidence with others of what MCs do is also key (CMOC 64).

Internal relationships and practices

The CMOCs in Table 3 relate to the relationships and working practices of people and groups within the body that runs the MC. As such these CMOCs, along with the conceptual model in Figure 2, mostly relate to the primary processes (micro level) of implementing/sustaining an MC, with come exceptions: CMOC 74 also relates to social context (meso level) and CMOCs 80-81

Table 1. Number and role of participants in interviews and focus groups (total *n* = 77).

Role in relation to MC	No. interviewed individually	No. interviewed as a pair	No. taking part in focus groups
Attendees	10 (5 male/5 female)	4 (2 male/2 female)	4 (2 male/2 female)
Attendees supporting someone with dementia (carers)	4 (1 male/3 female; 2 spousal/2 adult child)	2 (2 female; 2 spousal)	7 (2 male/5 female; 6 spousal/1 adult child)
MC staff & volunteers	16 (10 staff/6 volunteers)		1 (1 volunteer)
MC trustees & governance	11		1
Professionals & other stakeholders external to MC	14 (8 health and care professionals/6 other)	2 (2 health and care professionals)	1 (1 health and care professional)

External Relationships

A system to embed the Meeting Centre in the community and establish a clear and distinct position in the local health and social care system in order to maximise the Meeting Centre's reach and impact for all potential beneficiaries.
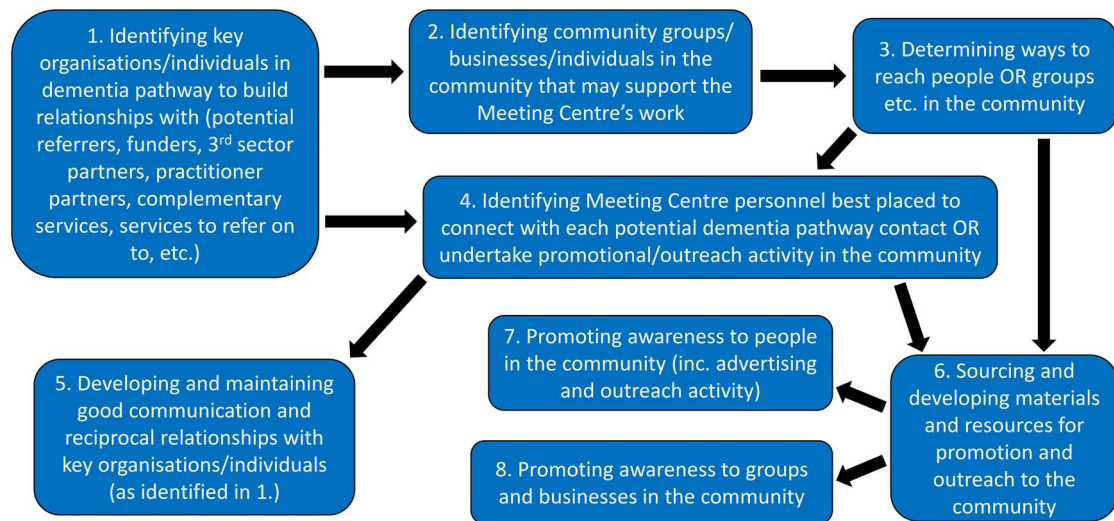
1. Identifying key organisations/individuals in dementia pathway to build relationships with (potential referrers, funders, 3rd sector partners, practitioner partners, complementary services, services to refer on to, etc.)

2. Identifying community groups/businesses/individuals in the community that may support the Meeting Centre's work

3. Determining ways to reach people OR groups etc. in the community

4. Identifying Meeting Centre personnel best placed to connect with each potential dementia pathway contact OR undertake promotional/outreach activity in the community

5. Developing and maintaining good communication and reciprocal relationships with key organisations/individuals (as identified in 1.)

7. Promoting awareness to people in the community (inc. advertising and outreach activity)

8. Promoting awareness to groups and businesses in the community

6. Sourcing and developing materials and resources for promotion and outreach to the community

Figure 1. Conceptual model of the MC 'external relationships' system.

Internal Relationships

A system that encourages good internal relationships - sharing skills, experience, ethos and goals, and understand each other's roles, preferences and needs – so that a Meeting Centre can run effectively and consistently on an ongoing basis to maximise benefit for all stakeholders.

1. Establishing and maintaining EITHER 1) an active board of trustees OR 2) a governance and management team with necessary time, skills, experience and connections

2. Determining roles, and the skills and staffing levels required to fulfil them

7. Monitoring staff and volunteers needs: that they feel able to carry out their roles and valued

3. Employing skilled staff

4. Recruiting appropriate volunteers

8. Maintaining person-centred ethos across personnel and activities with authentic input from members

6. Staff and volunteers carrying out roles effectively, with good team communication

5. Providing/accessing appropriate training staff and volunteers

Figure 2. Conceptual model of the MC 'Internal relationships' system.

relate to either inter-organisational context (meso level) or the health and care system around MCs (macro level).

How the people directly involved in running MCs work together, the decisions they make and what they do, is crucial to whether an MC will be successful long term. Whether managers, staff, volunteers or trustees, having skilled, motivated individuals working together with the right ethos and approach is key to maintaining an appealing and sustainable MC that meets a wide range of needs. CMOCs 65-75 outline learning regarding the recruiting and deployment of personnel in running an MC. Regarding practice, a person-centred provision that attends to members' needs and preferences (see CMOCs 76-77) was seen as crucial to sustaining MCs as MCs. If not maintained, 'mission drift' could result, with an MC failing to sustain as intended. This drift towards a different purpose or practices could result from staff and volunteers not understanding or working in line with the MC

ethos (CMOC 78-79), or from outside pressures from the health and care pathway/potential funders (CMOCs 80-81).

Finances and funding

The CMOCs in Table 4 relate to financial matters, in particular meeting costs and obtaining external funding. CMOCs 82-89 and 94 regard the impact of decisions made by MC trustees/governors, managers or staff at the micro level of implementing/sustaining an MC (i.e. about primary processes or how the MC is run day-to-day) but will be affected by conditions at meso (inter-organisational/social) and macro (health and care systems and policy) levels. CMOCs 90-93 regard conditions at meso and macro level more explicitly.

Funding for third-sector or grass-roots initiatives such as MCs is sparse and difficult to find, hence good financial

Finance

A system that provides financial stability for on-going payment of staff and volunteers costs, costs of premises and other running costs so that all Meeting Centre stakeholders feel safe and confident that there will be continuity of provision.
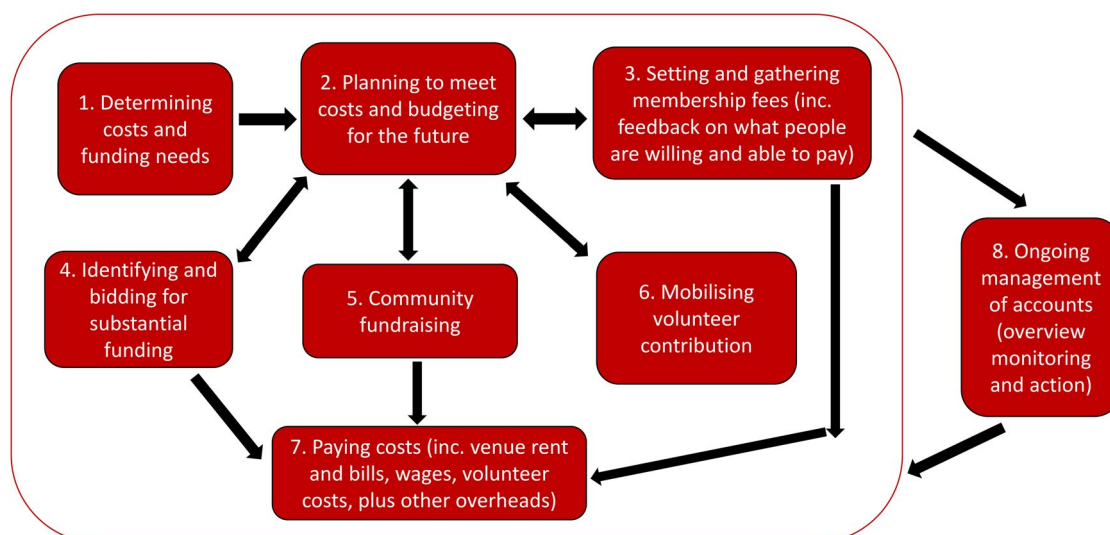
Figure 3. Conceptual model of the MC 'finance' system.

Table 2. CMOCs pertaining to external relationships and collaboration.

CMOCs by topic	Positive or negative for sustainability
Community building	
CMOC 53: If an MC has a presence/connections in the community then it is more likely to be supported as it will raise the awareness of people in that community and act as a focus/hub for dementia-supportive activity.	Positive
CMOC 54: If a community is closeknit then an MC is more likely to be successful because people will already be used to joining in to support group initiatives and each other.	Positive
Partnerships and networks	
CMOC 55: If an MC can show local agencies, organisations and the community that it is a useful and reliable resource, then it is likely to be supported and promoted by them because it will be valued and trusted.	Positive
CMOC 56: If an MC can develop and maintain strong partnerships and networks with local agencies and organisations then it is likely to attract more members, support and funding because it will become more known and visible to them.	Positive
CMOC 57: If an MC does outreach activities with people and groups in the community then they are more likely to attract more members and support because the benefits of MCs will become more known and visible in the community.	Positive
CMOC 58: If an MC has knowledge of, and links with, groups and individuals in the community then it is more likely to offer a variety of activities and services as it will be able to draw upon a wider pool of expertise and resources to contribute to the life of the centre.	Positive
Organisational governance	
CMOC 59: If organisations at both local and regional level work together in a two tier system then MCs are more likely to sustain because they can pool different strengths, resources and reach.	Positive
CMOC 60: If there is tension/competition between organisations then an MC is less likely to sustain as there will be a lack of collaboration and sharing to get things done.	Negative
CMOC 61: If a large charity or authority takes over the running of an MC then the MC may be more likely to sustain as it will be able to call upon the existing infrastructure and resources of that charity.	Positive
CMOC 62: If a large charity or authority takes over the running of an MC, then sustainability of the MC or its ethos may be threatened because the charity/authority's agenda will take precedence over it.	Negative
CMOC 63: If a large charity or authority takes over the running of an MC they may struggle to make as good connections in the community as a grass-roots group as they may be less embedded in it.	Negative
Data collection and research involvement	
CMOC 64: If an MC is involved in research and/or collects performance and cost data then it increases its chances of sustaining as it will have some academic backing and evidence of its value to help get further support.	Positive

planning and management are needed, and tough decisions may need to be made, to keep an MC going (Figure 3). Decisions such as the range of provision on offer, pricing structure to members, and whether to focus on one MC or multiple MCs across a region, will have a major impact on costs and whether those costs can be met (see CMOCs 82-88).

As suggested by CMOCs 88 and 94, many MCs run on a combination of different income and funding streams and, for most, finding available external funding is a key part of supporting an MC to keep going. This requires time, expertise and dedication from those running the MC however (CMOC 89), and an MC's ability to get ongoing external support can be impeded in multiple ways by the policies, processes and foci of potential funders and the health and care system as a whole (CMOCs 90-93).

The above CMOCs were used to develop a series of recommendations: 29 for those running or overseeing MCs, four for people attending or considering attending an MC (living with dementia or caring for someone who is), one for health and social care professionals, and three for commissioners or potential funders. These can be found in supplementary file 3.

Discussion

External relationships and collaboration

The importance of networking, collaboration and partnership working for the sustaining of community-based DFIs was a major theme in the SCI-Dem review (Morton et al., 2021), and

Table 3. CMOCs pertaining to internal relationships and practices.

CMOCs by topic	Positive or negative for sustainability
Trustee make-up	
CMOC 65: If trustees have relevant background skills and connections then an MC is more likely overcome threats to sustainability because they will know what to do and be able to use their contacts, knowledge and experience to support the MC.	Positive
Personnel recruitment and practice	
CMOC 66: If an MC has an experienced and highly motivated individual or individuals driving it then it is more likely to overcome threats to sustainability as they will go above and beyond and have the skills and connections to call upon to make it work.	Positive
CMOC 67: If an MC is over-reliant on an individual or individuals then that may eventually threaten its sustainability as they may become overwhelmed or exhausted by the responsibility and burn out.	Negative
CMOC 68: If an MC expects volunteers to take on significant responsibilities and workloads in order to run then it may not sustain as they may find it too much to take on and commit to.	Negative
CMOC 69: If an MC relies solely on volunteers with informal agreements to drive and run it then it may not sustain as those people may drop out as their circumstances change.	Negative
CMOC 70: If staff do not have job security then an MC's provision may not be stable as it is less likely to be able to recruit and retain skilled an experienced people.	Negative
CMOC 71: If there is a large organisation behind an MC, then staffing is likely to be more stable as they will have greater resources and more developed infrastructure to draw upon for recruiting and deploying staff and volunteers.	Positive
CMOC 72: If MCs are widely geographically dispersed then sharing staff and volunteers may be difficult as they may not want to travel due to time cost and unfamiliarity with somewhere other than home.	Negative
CMOC 73: If an MC is a friendly welcoming and flexible environment for volunteers then it is more likely to recruit and retain them because they will enjoy and benefit from their volunteer work.	Positive
CMOC 74: If the community around an MC has people with personal experience of supporting people with dementia then this could be a good source of volunteers as they will understand the value of an MC and have relevant skills (e.g. friends and family of members or people with a health and social care background).	Positive
CMOC 75: If a person living with dementia has milder symptoms then they may take on a volunteering role within the MC as they may prefer to be more actively engaged and empowered.	Positive
Person-centred and ability focussed practice	
CMOC 76: If the structure of what happens at an MC is not flexible then the MC will struggle to deliver high quality person-centred provision because it will not be able to accommodate a range of needs and preferences.	Negative
CMOC 77: If staff do not have enough time to consult with all members then an MC will struggle to deliver high quality person-centred provision because it will not take account of and attend to each individual's needs and preferences.	Negative
Mission drift	
CMOC 78: If staff or volunteers are not trained and working together in line with the ethos of an MC then the quality of experience for members may be poor as staff and volunteers may veer away from well-planned, well-delivered, respectful, person-centred practice.	Negative
CMOC 79: If staff and volunteers at an MC do not all understand what MCs are trying to achieve or have a different agenda then an MC may suffer 'mission drift' and not sustain as originally intended because it will be pushed towards a different purpose or different practices.	Negative
CMOC 80: If the health and social care pathway does not support what MCs are trying to achieve then an MC may suffer 'mission drift' and not sustain as originally intended because it will be pushed towards a different purpose or different practices.	Negative
CMOC 81: If those holding the key resources needed to sustain MCs do not understand what MCs are trying to achieve or have a different agenda then an MC may suffer 'mission drift' and not sustain as originally intended because it will be pushed towards a different purpose or different practices.	Negative

substantiated in this research with MCs. Such collaboration has been identified as key to the success of DFIs in general (Thijssen et al., 2023) and MCs in particular (Meiland et al., 2005; Van Mierlo et al., 2018). This resonates with goals set out in the UK Health & Care Act, 2022, which has now formalised 'integrated care system' partnerships between healthcare services, social care, and community/third sector organisations. By working with services in the health and care pathway, MCs in particular have been shown to have the potential to aid early intervention and access to care for community-dwelling people (Szcześniak et al., 2018).

However, equally important for DFIs such as MCs is networking and collaboration outside of formal health and social care, as part of a dementia-supportive ecosystem within their local communities. This research suggests MCs can show leadership and act as a catalyst to create a community around them, in line with the principles of DFCs (ADI, 2016), an important secondary function beyond simply meeting the needs of their membership. Specifically, this research suggests that if small organisations at community level work together with larger regional organisations (e.g. at county level) to pool resources and knowledge, this can be particularly effective in boosting chances of long-term sustainability. Results with larger charities getting involved were felt to be mixed; while they could potentially bring better organisational infrastructure and resources, this was not a given, and they could have other priorities, methods at odds with the MC model, and be less grounded in the community. Independent grass-roots ownership of an MC could increase its chances of sustaining due to the single-minded, community-specific focus and drive of those running it, but this was also likely to lead to challenges with infrastructure and resources, for example ensuring job security and avoiding burnout for staff, and having enough time and expertise to seek funding and gather data. A strong message from this research was that if groups and organisations in the community dementia support sector are placed in competition with each other, this is unhelpful for sustainability of DFIs.

Internal relationships and practices

In line with the Essential Features of an MC (Brooker, 2020) a person-centred approach (Brooker & Latham, 2015; NICE, 2018) was expressed as key to an MC's functioning and place in the dementia support pathway. Again this substantiates existing research, where it has been found the participation of people with dementia and carers in the planning of things, to ensure their needs and wishes are met, helps facilitate the ongoing success of MCs (Van Mierlo et al., 2018), and DFIs more generally (Thijssen et al., 2023).

However, various pressures were revealed in this research that may drive an MC to veer away from its intended ethos, purpose and activities. For example, different priorities, needs and availability of support in the wider dementia care system around MCs (e.g. those referring in, providing resources or

Table 4. CMOCs pertaining to finances and funding.

CMOCs by topic	Positive or negative for sustainability
Meeting costs	
CMOC 82: If funds are significantly limited then an MC offer serving a variety of needs will not be sustainable because a well-rounded holistic service for all is costly.	Negative
CMOC 83: If an MC only has to run for one day a week or fortnight then it is more likely to be financially sustainable as costs are lower.	Positive
CMOC 84: If an MC does not have any budget for external practitioners/activity facilitators then it may not recruit and retain as many members as it will struggle to offer a varied, appealing and high quality range of activities for a range of needs and preferences.	Negative
CMOC 85: If an MC does not have sufficient members/attendance then it may not be able to keep running because it will not have enough income.	Negative
CMOC 86: If the pricing structure is not clearly and carefully set together with members then an MC will have problems meeting costs as it may be too expensive to attract members or bring in too little to meet costs.	Negative
CMOC 87: If a larger organisation takes over the running of multiple MCs then they may be more likely to sustain as there will be economics of scale and wider reach for fund raising.	Positive
External funding	
CMOC 88: If membership fees are kept affordable then some external funding will be necessary to keep an MC going because what members are likely to be willing or able to pay is not likely to be enough to cover full costs.	Negative
CMOC 89: If an MC has personnel dedicated to continually seeking and applying for external funding then it is more likely to sustain because new funding is always likely to be needed and obtaining it requires ongoing time and expertise.	Positive
CMOC 90: If funders only support short-term or new projects then MCs will struggle to become established long-term as they will be unable to plan ahead with confidence or have time to learn how activity can be supported sustainably.	Negative
CMOC 91: If local authorities and commissioning bodies do not see tackling social isolation as part of their remit then MCs will struggle to get substantial support from them because those bodies will not see MC's social model of support as a priority for their resources.	Negative
CMOC 92: If MC members have mild to moderate dementia without acute care needs then MCs will struggle to get substantial support for them from local authorities as they are less likely to be seen as priority or qualify for specific local authority/NHS support.	Negative
CMOC 93: If funders mainly focus upon acute and clinical interventions then an MC may experience mission drift towards offering acute and clinical care because those running it may feel that is necessary to capture funding and resources to keep going.	Negative
CMOC 94: If an MC has multiple and diverse income streams and pots then it is more likely to maintain some ongoing funding because smaller funding amounts are easier to capture, costs can be met piecemeal and if one stream stops others will still be available.	Positive

linking with MCs) might encourage MCs to shift their offer to something different than originally intended (e.g. day care-style respite provision for people with more advanced dementia); a lack of training and different agendas in staff and volunteers could also have this 'mission drift' effect. 'Mission drift' was usually unintentional and difficult to militate against, hence a significant concern for the sustainability of MCs as a distinct intervention, servicing a distinct gap in provision and targeted at a specific demographic.

Finances and funding

This research suggests MCs will struggle to offer a range of provision purely on income from members' fees, unless those fees are high. In nations such as Poland and the UK, DFIs such as MCs tend not to fit into existing categories for personal budget support (Van Mierlo et al., 2018), meaning that, while some members may be able to get financial help to attend, many will not, especially as MCs are aimed at those who may still be living relatively independently and not meet the threshold for extra local authority support. Hence some external income is likely to be necessary in order for MCs to be inclusive and accessible to many. However, the SCI-Dem review (Morton et al., 2021) found that external funding was a major challenge for DFIs in general, and the same issues were identified for UK MCs in this research: chiefly, a funding landscape that prioritises new projects and only offers short-term competitive grants, pitting groups that could be working together against each other, and requiring significant and ongoing time, energy and expertise to pursue, that staff and trustees in grass-roots groups with limited resources may not be able to meet.

Previous research found that in UK and Italy there was less support available from national organisations in implementing DFIs like MCs (Van Mierlo et al., 2018). The UK Government's care and support statutory guidance (based on The Care Act 2014 but currently being reviewed with the publication of the

Health & Care Act, 2022) includes the aim that "the care and support system works to actively promote wellbeing and independence, and does not just wait to respond when people reach a crisis point," with early intervention which "helps people retain or regain their skills and confidence, and prevents need or delays deterioration wherever possible" (DHSC, 2023). These aims include local authorities working with local organisations to tackle issues such social isolation, with initiatives such as community activities. However, from the point of view of DFIs such as MCs, there remain intractable problems in gaining meaningful formal recognition that such initiatives could contribute to these goals, and in gaining any long-term statutory funding to resource their activities. Health services and local authorities both may recognise the importance of initiatives like MCs that seek to tackle social isolation to delay acute problems, crisis and decline, but they still have a primary responsibility to meet the most acute medical and social care needs as they arise; hence funding for initiatives like MCs that follow a social model of support is at present likely to be scarce, as is funding to support people to attend if their needs are not yet acute.

Exacerbating this is the challenge of demonstrating the effectiveness of community-based initiatives such as MCs in delaying decline to the standard that commissioners require, when such initiatives are often run by grass-roots community groups with limited resources, often dealing with relatively small numbers of people, struggling to sustain for more than a couple of years. Anecdotally, as in this research, there is no doubt such initiatives make a significant and valued difference to individual's lives, but demonstrating this statistically is challenging due to the real-world complexity of the intervention. This leads to a 'chicken and egg' problem of community initiatives struggling to get support (financial or otherwise) from local and national authorities without hard data, while struggling to generate hard data without that support. Nevertheless, data collection is essential for individual DFI groups like MCs to be able to secure external funding for long-term sustainability.

Recommendations for practice and directions for future research

A full list of recommendations from this research is given in supplementary file 3. Key recommendations include that smaller (local) groups and larger (regional or national) organisations explore how they might work together to pool strengths and resources, and avoid overlap or competition of services - but not that the running MCs be taken over wholesale by a national charity, as this may lead to the loss of the community-led focus of MCs. Those running MCs should ensure that they are run as intended according to the Essential Features of a Meeting Centre (Brooker, 2020), staying vigilant to unintended or undesired 'mission drift', and ensure that staff and volunteers always have MC training so they understand the purpose and ethos of Meeting Centres. Improving individual MCs' ability and motivation to collect data and present evidence must be a priority if MCs as a whole are to garner more robust external support and investment.

This research shows that there is still much work to be done in understanding how health, social care and third sector/community services and support initiatives can most effectively work together in an integrated way, in order to create consistent, sustainable support for those affected by dementia across the pathway. In particular, future research could focus on bolstering evidence not just for specific formally-delivered psychosocial interventions, but for social model community-based DFIs in general, including around how such initiatives might be used to target specific gaps in the pathway and how they might improve their data collection to robustly demonstrate their benefits to the wider health and social care system. As with the wider DFC landscape (Hung et al., 2021), more attention is needed regarding how MCs or similar DFIs might serve people with dementia from a wider variety of socio-economic, ethnic and cultural backgrounds than they tend to currently.

Strengths and limitations

A strength of this study is that is gives a nuanced, realistic and pragmatic account of the areas that MCs need to pay attention to in order to maximise their chances of sustaining long term, with strong indications of what kind of practices to encourage or avoid to achieve this. Where there are intractable issues beyond the control of those running MCS, learning from this research has highlighted them and can be used to bring to bring them to the attention of key stakeholders in the wider dementia care landscape: for example those responsible for planning and monitoring health and social care pathways, for funding and commissioning services in the sector, and for setting strategy and policy around dementia at both a regional and national level. It has also largely validated, and added to, the learning from the SCI-Dem review (Morton et al., 2021).

The CMOCs in this study are specific to what was found at the participating MC sites, so they are not universally generalizable, but neither are they intended to be: it should be clear where different circumstances have led to different outcomes, and where there are likely to be transferrable learning points for other community-based initiatives/DFIs in similar circumstances. Another limitation is that often the learning from an exploratory study such as this cannot provide definitive solutions to some of the intractable problems identified, only an understanding of the issues and why and how they have arisen, but hopefully this can inform future decision making and help effect change where necessary.

Conclusions

Collaboration is essential for community-based support initiatives such as MCs to sustain, particularly between groups working at a local community level and organisations working at a regional level. Situations where dementia-supporting organisations are in competition with each other are therefore unhelpful. However, MCs need to be vigilant in mitigating external and internal pressures that might create 'mission drift', as targeting a particular gap in the dementia pathway and maintaining a person-centred ethos are central to MCs' appeal.

Careful planning and management of finances is necessary for DFIs such as MCs; though ultimately, stable, ongoing funding is needed for stable, ongoing community dementia support. More formal recognition of the value of social model community-based initiatives such as MCs by statutory bodies, and improved data collection from social-model community-based initiatives such as MCs to evidence this, would help create more robust and consistent community dementia support across the UK.

Disclosure statement

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Data availability statement

Data and study materials will be made available upon request from the corresponding author. This study was pre-registered with the ISRCTN, ref: 39861.

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